

**North Carolina
Department of
Health and Human Services
*Division of Medical Assistance***

***North Carolina Family Planning Waiver
Waiver Year One
Primary Care Referrals Focus Groups***

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EXECUTIVE SUMMARY

The North Carolina Department of Health and Human Services (DHHS) engaged Navigant Consulting, Inc. to provide an independent evaluation of the State's Family Planning Waiver, and determine the extent to which the Waiver objectives have been met—namely, whether there is improved access to Medicaid family planning services for low-income men and women, and if desired outcomes have been reached, including reduction of unwanted pregnancies, effective use of contraceptives, and maternal and infant health.

The Waiver includes a quality of care indicator to measure whether Waiver participants who lack a source of primary care at the time of enrollment in the Waiver will be referred to an appropriate source of such care. The Waiver Evaluation Plan specifies the use of focus groups with participants who have been enrolled in the Waiver for at least six months to explore their experiences in obtaining primary care referrals from their family planning providers, their success in following up on the referrals, barriers they may have encountered and their satisfaction with the referral process.

Navigant Consulting conducted four focus groups in June 2007 to assess primary care referrals under Year One (October 1, 2005 – September 30, 2006) of the Family Planning Waiver Program, known as “Be Smart.” Thirty-eight women participated in these focus groups, conducted in Wake, Pitt, Catawba and Guilford Counties. This first set of focus groups yielded some valuable information about the individual and collective experiences of Be Smart participants.

Most focus group participants reported successful results in Waiver Year One of Be Smart. The general sentiment is that family planning helps these focus group participants plan the size of family they need, while maintaining a healthy status. Relative to primary care referral services:

- Fifty-eight percent of focus group participants indicated that they had success obtaining a referral for primary care services.
- Focus group participants do not all indicate an awareness of the availability of primary care referral services. Further, it appears that information about referrals to primary care is disseminated inconsistently across consumer locations.
- For focus group participants, access to primary care referrals is also uneven. Some participants who had received primary care referrals identified the waiting time to get services, and unaffordable service alternatives as barriers to obtaining referral services.

- The pattern of follow-up for primary care referrals varies among sites.
- Participants who received primary care referrals were generally satisfied with the referrals.
- For healthy participants, the annual physical examination at the family planning site seems adequate for them to maintain a healthy status; a few focus group participants with health care problems expressed concern about the lack of available and affordable primary care when they are referred to these services.

Based on the results of these focus group discussions, as well as our experience in conducting focus groups in North Carolina and elsewhere, we believe the focus groups achieved the desired objective and recommend their use, with some improvements as we note in the report, in upcoming Waiver year evaluations.

The report which follows describes the objectives of the focus group discussions, the methodology for selection of focus group participants, characteristics of focus group participations and the methodology for conducting the focus group sessions, findings and issues and potential solutions identified from the focus group process.

SECTION I: INTRODUCTION

Overview

The North Carolina Department of Health and Human Services (DHHS), Division of Medical Assistance (“Division”), contracted with Navigant Consulting, Inc. to provide an independent evaluation of the State’s Family Planning Waiver (“Waiver”), operationalized as the “Be Smart” program, to determine the extent to which the Waiver objectives have been met. The objectives of the Waiver are to:

- Increase the number of reproductive age women and men receiving either Title XIX or Title X funded family planning services by improving access to and use of Medicaid family planning services.
- Reduce the number of inadequately spaced pregnancies by women in the target group, thus improving the birth outcomes and health of these women.
- Reduce the number of unintended and unwanted pregnancies among women who are eligible for Medicaid.
- Impact positively the utilization of and “continuation rates” for contraceptive use among the target population.
- Increase the use of more effective methods of contraception (such as Depo-Provera, IUD and sterilization) in the target population.
- Decrease the number of Medicaid paid deliveries, which will reduce annual expenditures for prenatal, delivery, newborn and infant care.
- Estimate the overall savings in Medicaid spending attributable to providing family planning services to women and men through this demonstration project.

The evaluation plan approved by the Centers for Medicare and Medicaid Services (CMS) for the Family Planning Waiver includes a quality of care indicator to measure whether Waiver participants who lack a source of primary care at the time of enrollment in the Waiver will be referred to an appropriate source of primary care. The Waiver Evaluation Plan specifies the use of focus groups with participants who have been enrolled in the Waiver for at least six months to explore their experiences in obtaining primary care referrals from their family planning providers, their success in following up on the referrals, the barriers that they may have encountered in the process and their satisfaction with the referral process.

SECTION II – METHODOLOGY

In this section, we describe the evaluation questions that the focus group process is intended to address, the process we used to identify focus group participants and obtain their participation, the characteristics of the participants in the focus groups and the focus group process.

Evaluation Objectives

The Family Planning Waiver sets forth the hypotheses to be tested to determine if the Waiver program meets the established objectives. The Waiver Evaluation Plan approved by CMS is designed to measure the overall impact of the Waiver. The overall evaluation includes a retrospective cohort study and a process evaluation. The retrospective cohort study involves secondary analyses of information routinely obtained at the State Center for Health Statistics as well as Medicaid claims data. The process evaluation includes a standard set of quality of care indicators. One of the specific process and quality indicators is represented as Hypothesis D.1.2.:

“Increased proportion of Waiver participants lacking a source of primary care at the time of their enrollment in the Waiver will be referred to an appropriate source of care: To evaluate the extent of participants’ follow-up on primary care referrals received from their family planning providers, we will report results from at least 4 focus groups held annually with enrollees participating in the program for at least 6 months. The composition of the focus groups will be based on the demographic and geographic distribution of enrollees. We will explore their experiences in obtaining primary care referrals from their family planning providers, their success in following up on the referrals, barriers they may have encountered in either process and their satisfaction with the referral process.”

Process Used to Identify Focus Group Participants and Obtain Their Participation

Through discussions with Division representatives and based on our experience in conducting focus groups for a previous Waiver evaluation for North Carolina as well as focus groups in other states, we determined the optimal approach to identifying potential focus group participants was to ask County providers to assist. We made this decision for a number of reasons:

- The County Health Departments are generally the largest providers of family planning services in the State. This meant that the County Health Department staff were very familiar with the Waiver and had access to the greatest number of participants in their counties.
- The County Health Departments have existing relationships with participants and understand the challenges that might be encountered in obtaining focus group participants. A representative of a County Health Department suggested that because of their existing relationship with participants, Health Department representatives would be the best initial contact to identify willing participants; other County Health Department representatives concurred. The County Health Departments also agreed to provide a venue for the focus groups because they had the space to hold meetings and the participants were familiar with the location.
- The County Health Departments also maintained the most accurate contact information about Waiver participants who had received services. Through discussions with the State and County Health Department staff, we determined that the County Health Departments would have the most up-to-date information about participant address and phone number. This was important for the County Health Departments to initiate interest in the focus group and for us to use that information to conduct reminder phone calls prior to the focus groups.

We recognized that there could be some potential issues related to bias in selection of focus group participants given the providers' roles in the notification of potential focus group participants. To reduce the chance of provider bias, we gave each County Health Department a list of eligible consumers who we had prescreened for eligibility. The universe of eligible consumers (from 40 eligible consumers from Pitt County to 350 from Wake County) for each focus group location was relatively small, and the likelihood of provider bias in the selection of focus group participants was minimized by the limited number of Waiver participants from whom to recruit.

We selected four County Health Departments to assist us in soliciting participation for the focus groups from the Waiver participants they serve. We selected these four Health Departments due to their geographically diverse locations throughout the State, as well as the comparatively large number of consumers who received services from them during Waiver Year One (October 1, 2005 to September 30, 2006). These Health Departments were Wake County Human Services, Pitt County Public Health Center, Catawba County Public Health and Guilford County Department of Public Health.

We selected each of these counties for the following reasons:

- Wake County – Large, urban county in the central region of the State, ranks first in the number of Waiver participants
- Pitt County – Relatively medium-sized county in the eastern region of the State, provides a mix of urban and rural and ranks 18th of 100 counties in the number of Waiver participants
- Catawba County – Similar in size and urban/rural mix as Pitt County, western region of the State and ranks fifth in terms of the number of Waiver participants
- Guilford County – Large, urban county in the central region of the State, ranks second in the number of Waiver participants

For the Year One evaluation focus groups, we were concerned with capturing focus group participation from different geographic areas of the State and we concentrated on the County Health Departments with the highest number of Waiver participants to improve our chances.

We had originally proposed to the Division that we would conduct three female focus groups and one male focus group for the Year One evaluation. (We determined it would be most appropriate to conduct separate male/female focus groups.) However, there was no single provider that served more than five male participants during Year One of the Waiver program and we would have had to work with numerous providers in a single county to identify a sufficient number of potential male focus group participants.¹ Given the amount of time needed to work with the providers to identify focus group participants, and based on our concerns that we complete the focus groups in a timely manner, for the Year One evaluation, we recommended that we would conduct focus groups with only females. The Division concurred with this recommendation. We plan to conduct a male focus group for the Year Two evaluation.

We initially chose a County Health Department from western, central and eastern North Carolina, and as we determined difficulty to obtain participation for an all male focus group, we added a fourth, large county, also from the central part of the State, to improve the likelihood that we could attract enough participants.

In addition, we wanted to include a provider type different from the County Health Departments. We received assistance from Planned Parenthood Health Systems Inc. of

¹ There were a total of 97 male waiver participants in Year One.

Wake County. Planned Parenthood of Wake County was willing to recruit participants to attend the focus group meeting at the Wake County Health Department. We presented our recommendations to the Division and Division representatives agreed with the selection of counties.

The Division provided us with a list of Medicaid ID numbers for Year One Waiver participants in the four counties we selected. We provided those Medicaid ID numbers to the County Health Departments so that the Health Departments could contact Be Smart participants to invite them to participate in the focus groups. The Health Departments matched the Medicaid IDs to the names of the Be Smart participants and verified that the service they provided to the individual was provided during Waiver Year One. The Health Department contacted the Be Smart participant to invite her to the focus group. We verified that the individuals registered met the qualifications of participation in the focus groups.

To be eligible to participate in the focus group, participants must have been eligible for the Waiver for at least six months and must have received a service in Waiver Year One (October 1, 2005 to September 30, 2006). Staff of the respective County Health Departments and Planned Parenthood Health Systems Inc. of Wake County placed the initial calls to eligible Be Smart enrollees to invite them to participate in the focus groups.² We offered consumers \$25 in cash if they participated in the focus groups, as well as food and refreshments during each of the focus groups. Each County Health Department had a goal of obtaining 25 verbal commitments from consumers to participate in the focus group, with the understanding that the number of actual participants would be lower due to a certain number of “no-shows” for each group. Wake County Human Services and Planned Parenthood collectively shared this goal. Combined, the four counties and Planned Parenthood were able to obtain 79 verbal commitments.

A week prior to the first focus group, Navigant Consulting made telephone calls to those consumers who had verbally committed to participate to remind them of the time, date and location of the focus group, as well as the \$25, food and refreshments that they would receive upon arrival.

Focus Group Participants

Of the 79 consumers who agreed to participate, 38 actually attended the focus groups. Table 1 on the following page details the number of focus group participants per county.

² Wake County Department of Human Services also distributed flyers to eligible consumers who came for their scheduled appointments beginning Wednesday, June 6 through June 16. Wake County Department of Human Services also placed a flyer in the clinic waiting room.

Table 1: Year One (2006) Family Planning Waiver Consumer Focus Groups Participation

Date	Location	Number of Registered Participants	Number of Actual Participants
June 25	Wake County Human Services ³	25	14
June 26	Pitt County Public Health Center	12	7
June 27	Catawba County Public Health	25	9
June 28	Guilford County Dept. Of Public Health	17	8
Total		79	38

The 38 women who participated in the focus groups varied in terms of racial backgrounds and ages. Table 2, on the next page, details the demographics of the focus group participants by focus group site.

As Table 2 demonstrates, the majority of the women overall participating in the focus group – 34 percent – were between the ages of 19 and 24. County-by-county, there was some variability in age. In Catawba, for example, the majority of women were between the ages of 35 and 39 and in Pitt County, the majority of women were between the ages of 25 and 29.

³ Number includes three verbal commitments from consumers at Planned Parenthood Health Systems Inc. of Wake County.

Table 2: Year One (2006) Family Planning Waiver Consumer Focus Group Age Distribution of Participants By County and Age of Participant

Location	Number of Participants	Age 19-24	Age 25-29	Age 30-34	Age 35-39	Age 40-55
Wake County Human Services ⁴	14	3	3	4	3	1
Pitt County Public Health Center	7	2	4	0	1	0
Catawba County Public Health	9	2	0	2	4	1
Guilford County Dept. Of Public Health	8	6	1	1	0	0
Total	38	13	8	7	8	2
Percent of Total	100%	34%	21%	18%	21%	5%

For comparison, we reviewed the distribution of age of enrollees statewide, in Table 3 below.⁵ The distribution of the ages of focus group participants was comparable to the statewide age distributions of enrollees.

Table 3: Age Distribution of Family Planning Enrollees

Age Group	Percentage
Age 19-24	43%
Age 25-29	22%
Age 30-34	14%
Age 35-39	10%
Age 40-55	11%
Total	100%

⁴ Number includes three verbal commitments from consumers at Planned Parenthood Inc. in Wake County.

⁵ Enrollees are defined as individuals who qualify to receive family planning services through the waiver, but may or may not have had a service, i.e., "participated," during the first waiver year.

The majority of focus group participants were African American (61 percent) as shown in Table 4 below.

Table 4: Racial/Ethnic Background of Focus Group Participants⁶

Race/Ethnicity	Number	Percentage
White	9	24%
African American	23	60%
Asian	1	3%
Multi-racial	1	3%
No identification	4	10%
Total	38	100%

For comparison, we examined the racial/ethnic background of family planning Waiver enrollees across the State, as shown in Table 5 on the next page.⁷ We did not select focus group participants using a statistical, random sampling approach; we relied on the willingness of the enrollees to take part in the focus group. African Americans are the majority of enrollees in the Waiver (47 percent), at 60 percent the focus group participants overrepresented African Americans and underrepresented Whites. Since indicating race or ethnicity was optional for focus group participants, it is possible that this discrepancy is partly accounted for by those who chose not to indicate their race or ethnicity on the focus group sign-in sheet.

⁶ Focus Group participants were given the option of identifying racial/ethnic background on the sign-in sheets. For future focus groups we will provide choices for race and ethnicity for participants to select on the sign-in sheets and specifically include Spanish/Hispanic/Latino as an option to count this ethnicity.

⁷ Enrollees are defined as individuals who qualify to receive family planning services through the waiver, but may or may not have had a service, i.e., "participated," during the first waiver year.

Table 5: Racial/Ethnic Background of Family Planning Enrollees

Race/Ethnicity	Percentage
White	45%
African American	47%
Asian ⁸	3%
No identification	5%
Total	100%

Process Used to Conduct the Focus Groups

Because of the sensitivity of family planning as a topic for discussion in a large group, we believe there are inherent challenges to encouraging female consumers' attendance and active participation. The Navigant Consulting focus group leader took a number of steps to promote a degree of comfort:

- Used a standard script to assure participants of the protection of confidentiality and privacy; the focus group leader repeated these assurances throughout the proceedings
- Eliminated taping of the focus group session, a standard procedure used for most focus groups
- Used an individual sign-in sheet instead of a group sign-in sheet for focus group participants
- Secured the master list of registered individuals
- Sought the group's permission to allow a local health department staff to observe the proceedings (this took place at one location)
- Provided refreshments and beverages, as well as a stipend for attending, as discussed above

Because of the precautions regarding confidentiality taken with the female consumers, all four focus groups proceeded as planned, and participants were active and interactive with one another. Indeed, one of the most salient features of the focus group format for

⁸ The category for Asian includes Asian, Pacific Islander or Native Hawaiian, and American Indian or Alaska Native.

female consumers was the opportunity for the participants to learn from the experiences of others. By the end of each focus group, the Navigant Consulting focus group leader observed that the focus group participants continued their discussions outside the meeting room, evidencing an interest in further networking.

There are natural positive features of the focus group format for female consumers:

- Most of the enrolled consumers appeared comfortable in a face-to-face environment
- Participants have shared common experiences as either former Temporary Assistance for Needy Families (TANF) recipients or working poor ineligible for Medicaid
- A small group of young women had been children in the TANF program
- Participants seemed comfortable in sharing their own experiences with the Waiver program

SECTION III: FINDINGS

Below, we present our findings from the four focus groups. We describe findings related to each of the structured focus group questions and provide a summary of overall findings, with observations according to age and racial/ethnic background of the participants.

Responses to Structured Focus Group Questions

We developed a set of structured focus group questions with follow-up questions. Although the objective of the focus group was to assess referrals to primary care services, we also asked other questions about the Waiver program to develop a context for questions about primary care referrals. We provided this list of questions to the Division for its review. Based on Division staff suggestions, we made some revisions and the Division approved the final focus group questions. We have provided these questions in Appendix A.

We used these questions for all four focus groups; responses to and discussion related to each question are summarized below. To protect consumer and provider confidentiality, we have not provided a summary of responses by age, racial/ethnic background and geographic area.

1. Have enrollees indicated that they heard about Waiver services from one or more sources?

Most of the focus group participants reported that they received the information about Be Smart from a local health or public health department staff member, e.g., nurse or social worker. Many participants have also seen public bulletin notices posted at the local health or public health department. A small number of participants have heard of the program from their neighbor or friend.

The majority of the focus group participants indicated these common experiences:

- They were offered the family planning Waiver when they received news about their loss of Medicaid eligibility due to a change in income level.
- They were offered the family planning Waiver during an annual physical exam at the health/public health department.

The majority of focus group participants have been enrolled in the program for more than a year, with the shortest enrollment period being three months.⁹ Most participants

⁹ Although we attempted to identify only those individuals who had participated in Be Smart for at least 6 months, we identified through the focus group process two individuals who had not been enrolled for that length of time.

reported the enrollment process was relatively smooth, and, in many cases, the participant was enrolled on the same day that her eligibility was determined. Participants reported that the enrollment was easier when the staff responsible for enrollment also handled Medicaid eligibility, thus expediting the income verification process. Participants received some general information about the program, but no written brochures. Only one participant had seen the Be Smart pamphlet issued by the Division of Medical Assistance.

While the enrollment process was reasonably smooth, participants whose eligibility for Be Smart terminated reported problems with the disenrollment process when their income levels had changed. The termination was considered too abrupt without any transition, which they reported as necessary. This created certain hardships with the high cost of birth control medication and other pending medical procedures.

There were other areas of concern:

- Focus group participants were not generally aware of the need to recertify, and when they did not receive a renewed family planning Waiver card, they mistakenly assumed that they had been terminated. In fact, many of those who attended the focus group meeting were under the impression that they had lost their eligibility for Be Smart.
- The Be Smart eligibility card is the same color (blue) as the regular Medicaid card, leading some focus group participants to assume that they had Medicaid eligibility. In most cases they quickly discovered that this was not the case.
- Only one focus group participant was aware of the fact that men are also covered. Participants felt that insufficient communication and public education were responsible for this gap in outreach. In fact, at one focus group meeting, the entire group of participants indicated that they had no prior information about Be Smart being available to low-income men.

Many participants had other health care issues beyond family planning concerns, and the Waiver coverage, while limited, nevertheless provided a safety-net function. Several women who could not bear children indicated that they participated not for the family planning benefit, but for the benefit of receiving an annual check-up.¹⁰

Because the enrollment process and information disseminated seemed to vary from site to site, one striking finding is that at one location, all women reported that they had

¹⁰ One requirement for participation in the waiver is that the person is “not permanently sterilized.” We did not determine from these focus group participants whether their inability to bear children was a perception of their own condition or that they were permanently sterilized.

received no written information about services for which they might be eligible, and none about primary care referrals.¹¹

2. *Are participant women less likely to be lost to follow-up?*

Most of the focus group participants indicated that once enrolled in Be Smart, they received reminders about annual checkups and other related family planning visits. However, it was up to them to make the follow-up appointments. At one location, the participants reported that there were no reminders from the local health/public health department. Because Be Smart services may be the only health care services participants receive, motivation for follow-up is high.

A point of comparison would be focus group participants' experience before the Waiver. The majority of participants in the focus groups indicated that the Waiver allowed them to practice a basic health maintenance that would not have been available or affordable in the absence of Be Smart. However, a small number of the participants wondered about the viability of Waiver services, given the impression they have received from their local health/public health officials that they are "on their own" if their annual check-up or screening shows abnormality.

Family planning services require regular follow-up, e.g., continued use of certain contraceptives depends on medication renewal or periodic and regular visits to receive DepoProvera. Only IUD or voluntary sterilization does not require a follow-up, but annual check-up ensures continuation with the program. Only one focus group participant skipped a follow-up visit as a result of moving to a different apartment.

3. *Are participant women more likely to report continuous use of a contraceptive method? Are participant women more likely to report use of a highly effective method of contraception?*

The focus groups participants all reported use of a contraceptive method, with varying degree of success. Most complaints came from users of DepoProvera, who expressed concerns about weight gain or weight loss, prolonged bleeding and loss of calcium content (problems with bone density).

¹¹ The Division of Medical Assistance and the Division of Public Health tasks the local social services department with providing waiver applicants with a packet of materials that includes information on the local availability of primary care providers and explaining how to obtain family planning services and primary care services verbally to the applicant. Case managers are requested to note the exchange of information in the individual's file. It is possible that the focus group participants had difficulty recalling this detail of the enrollment process since it would have occurred more than 12 months prior to the focus group meeting.

4. *Are there longer inter-pregnancy intervals among Waiver participants? Are there lower unintended pregnancies among Waiver participants?*

Most focus group participants reported successful results from the Waiver program. The general sentiment is that family planning helps them plan the size of family they need, while maintaining a healthy status. Four participants out of the entire sample reported unplanned pregnancies while using contraceptives; one of them decided to undergo voluntary sterilization following unsuccessful use of other contraceptives, and the other three carried their pregnancies to full term, including one older woman who was delighted with the pregnancy, having had difficulty conceiving in the past.

Due to the insufficient enrollment time of the participants (i.e., participants were enrolled in the program a maximum of 12 months), they were not able to answer the question about interval between pregnancies. However, they indicated that prior to entering the Waiver program, they had experienced unplanned pregnancies.

5. *What are Waiver participants' experiences in obtaining primary care referrals from family planning providers?*

We noted inconsistencies in responses related to this question, however, responses ranged from a general unawareness of the referral services to good information with follow-up support. Fifty-eight percent (22 participants) of focus group participants reported that they received primary care referrals and 42 percent (16 participants) reported difficulties in obtaining a referral. Table 6 on the following page, shows the count of focus group participants who were able to obtain a primary care referral and who had difficulties obtaining a referral.

Many focus group participants were confused about the nature of the primary care referrals, given their varied individual experiences. Some were referred to local hospitals for services and then were billed a substantial amount which they had difficulty paying. Others obtained assistance in making an appointment with a primary care physician who was willing to see low-income consumers, or free clinics operated by religious and civic organizations. Others attempted to locate primary care services on their own or through their own network (e.g., friends, churches).

One of the interesting features of the focus group format is information exchange about primary care referrals. Within each group, many participants were learning for the first time what is available in primary care referrals. They also shared their own experiences, both positive and negative, with others.

Table 6: Count of Primary Care Referrals for Focus Group Participants

	Total
Focus Group Participants	38
Indicated Ability to Obtain Primary Care Referral	22
Indicated Difficulty in Obtaining Primary Care Referrals	16
Percent of Participants Who Had Success Obtaining a Primary Care Referral	58%

Generally speaking, focus group participants with primary care referrals were satisfied with the services, with the only concern about waiting time. In some of the urban ministry type of primary care organizations, two days out of a week are set aside for a free clinic. Some local hospitals also offer free clinic visits, but with limited time and allotments. Others reported favorable experiences with walk-in clinics where no appointments are needed, but the treating physician does not take any Medicaid or insurance coverage (to reduce paper work burden) and allows patients to pay based on financial ability. In one focus group, members shared their frustration in not being able to find suitable primary care alternatives for services not covered by the local health/public health agency.

The focus group participants were unanimous in their suggestion that the information about the primary care referrals should be part of their enrollment packet. During each focus group, the Navigant Consulting focus group leader distributed a state-issued brochure, "Be Smart. Be Ready." All participants indicated that it was the first time they saw the brochure, although some of the information contained had been shared with them by the local health/public health department official.

6. How successfully do Waiver participants follow up on primary care referrals obtained from family planning providers?

The focus group participants indicated that they wasted no time in following up on primary care referrals because at the time of the referral, they needed medical attention. Only one participant had the referral information without using it, explaining that she was saving it for future reference.

The pattern of follow-up varies among focus group participants at the different sites. For those participants who received referrals, some local health/public health departments make the referral on behalf of the Waiver participant; others leave it to the

participants to make the referral. The former appeared to have the higher compliance rate, however, given the need for these primary care referrals, participants in the focus group did not see follow-up as a problem. They generally contacted the primary care referral within a week, if not on the same day.

7. What are the barriers faced by Waiver participants in obtaining primary care referrals from family planning providers?

Focus group participants reported that the selection of primary care providers is rather limited. The participants were given one or, at the most, two referrals to contact. They explained that this was the result of the small number of primary care physicians who are willing to treat the low-income women. At one location, primary care referrals were never provided to the participants in the focus group. During the focus group discussions, the participants were queried about their use of emergency room or urgent care. More than 80 percent of the women have made use of these services when in need.

Another barrier is related to the lack of affordable treatment once problems are discovered during an annual check-up or OB/GYN screening. Many participants stated that this might hamper their compliance with regular check-ups: "What is the point of getting screening if you can do nothing about treating the problems identified?"

8. What is the level of satisfaction of Waiver participants in obtaining primary care referrals from family planning providers?

Other than the limited number of available primary care referrals that are affordable to the focus group participants, once the access is assured and the payment is affordable, the participants were generally satisfied with the services. One recurring concern is the waiting period; some primary referrals would take a long time to schedule.

Summary of Findings

This first set of focus groups yielded some valuable information about the individual and collective experiences of Be Smart participants, and demonstrates that a focus group format can be a viable means for collecting data to answer evaluation questions.

As reported above, most focus group participants reported successful results from the Waiver program. In addition, most participants in the Waiver were satisfied with their primary care once the referrals were successfully made. In addition, the general sentiment is that family planning helps participants plan the size of the family they want, while maintaining a healthy status.

Below, we summarize the major findings related to primary care referral services.

- **Slightly less than 60 percent of focus group participants indicated that they were successful at obtaining a referral for primary care services.**

The results varied by county for focus group participants who were successful at obtaining a primary care referral. We will collect data for this statistic at subsequent Waiver year focus groups and will comment on the trend of difficulty obtaining referrals for primary care services over the life of the Waiver.

- **Focus group participants do not all indicate an awareness of the availability of primary care referral services. Further, it appears that information about referrals to primary care is disseminated inconsistently across consumer locations.**

Some focus group participants were generally unaware of the primary care referral services; others were aware and indicated that they received support with follow-up. Some participants were learning for the first time in the focus group about what is available in primary care referrals. However, the majority of participants were actively involved in seeking primary care for themselves and others, and there was a strong element of self-help and mutual-help in their approach to health care.

Many focus group participants, however, were confused about the nature of the primary care referrals, given their varied individual experiences. Some obtained assistance in making an appointment with a primary care physician willing to see low-income consumers, or free clinics operated by religious and civic organizations. Others attempted to locate primary care services on their own or through their own network (friends, churches).

During each focus group, the Navigant Consulting focus group leader distributed a state-issued brochure, “Be Smart. Be Ready.” All participants indicated that it was the first time they saw the brochure, although some of the information contained in those brochures had been shared with them by the local health/public health department official. In one location, the local health department official indicated that the information contained in the state-issued brochure had been incorporated in the local user’s manual.

The participants were unanimous in their suggestion that information about the primary care referrals should be part of their enrollment packet.

- **For focus group members, access to primary care referrals is also uneven. Some participants who had received primary care referrals identified the waiting time to get services, and unaffordable service alternatives as barriers to obtaining referral services.**

Many focus group participants indicated that they were able to access services from some of the urban ministry type of primary care organizations, where two days out of a week are set aside for a free clinic. A number of participants also reported that some local hospitals also offer free clinic visits, but with limited time and allotments. Other participants reported favorable experiences with walk-in clinics where no appointments are needed, but the treating physician does not take any Medicaid or insurance coverage (to reduce paper work burden) and allows patients to pay based on financial ability. Several participants in one group shared their frustration in not being able to find suitable primary care alternatives for services not covered by the local health/public health agency.

The majority of focus group participants reported that the selection of primary care providers is rather limited. The participants were given one, or at the most, two referrals to contact. They explained that this was the result of the paucity of primary care physicians who are willing to treat the low-income women.

- **The pattern of follow-up for primary care referrals varies among sites.**

Some local health/public health departments make the referral on behalf of the focus group participant; others leave it to the participants to make the referral. The former appeared to have the higher compliance rate, however, given the need for these primary care referrals, participants in the focus group did not see follow-up as a problem. They generally contacted the primary care referral within a week, if not the same day. The participants

indicated that they wasted no time in following up on primary care referrals because at the time of the referral, they needed medical attention. Only one participant had the referral information without using it, explaining that she was saving it for future reference.

- **Participants who received primary care referrals were generally satisfied with the referrals.**

One recurring concern (in addition to the financial barriers described above) is the waiting period; some primary referrals took long time to schedule. However, most of the focus group participants were satisfied with the quality of services they received from the primary care referrals; they usually returned to the same primary care referrals for follow-up treatment.

- **For healthy focus group participants, the annual physical examination at the family planning site seems adequate for them to maintain a healthy status; a few with health care problems are concerned about the lack of available and affordable primary care.**

It is important to view the access to primary care referral in the context of the health status of the participants. For the most part, the participants have reported general good health, and an annual physical check-up seems sufficient to meet their needs. A limited number of the participants reported that they do suffer other health ailments that require timely referrals to primary care, and for this group, the Waiver program could do more to improve their access to services.

- **It is significant that responses to Focus Group Questions varied according to the age and racial/ethnic background of the participants in a number of ways.**

The older focus group participants (36 to 45 age group) are more positive about the Be Smart program, viewing as a significant benefit access to family planning. One woman, for example, through the assistance of the family planning program, was able to achieve her family planning goal when all previous efforts had failed; another woman was able to conceive after many years of unsuccessful attempts. The youngest focus group participants (19 to 25 age group) are more vocal about their concerns about access to primary care services. More African American participants than other racial/ethnic groups have expressed their concerns about the lack of affordable primary care referrals; this may be a reflection of the more than majority (61 percent) of their representation in the sample.

SECTION IV: LESSONS LEARNED AND RECOMMENDATIONS FOR IMPROVING THE FOCUS GROUP APPROACH

In this section, we have identified a number of “lessons learned” about the focus group approach and recommendations related to improving the approach for Years 2 – 5 of the Waiver evaluation. We also discuss approaches other States have used for evaluating primary care referrals in family planning waivers and focus group approaches used by States in the evaluation of waiver programs.

Focus Group Logistical Issues and Potential Solutions and Challenges for Subsequent Year Focus Groups

There were a few logistical issues that presented challenges during the first year focus groups and that may present challenges to us as we conduct focus groups for the remaining four years of the Waiver evaluation period. In Table 7 below, we list and describe the issue and potential solutions to resolve these issues, as well as additional challenges in conducting the Waiver Year Two focus groups.

Table 7: Focus Group Issues and Potential Solutions/Additional Challenges

Issue	Description	Potential Solutions/Additional Challenges for Year Two Focus Groups
Lag time between the Waiver year under evaluation and the focus group	We conducted the first four focus groups to evaluate the performance of the Waiver performed during its first year of operation (October 1, 2005 to September 30, 2006). Because of the delay in awarding the contract for the Waiver evaluation, the focus groups were conducted nearly nine months after the end of the Waiver’s first year. Such a lag time may have made it more difficult to obtain focus group participants because some may have moved and/or had their telephone number may have changed. Additionally, such a lag time may have made it more difficult for the focus group participants to remember important details about the services they received in the first year of the program.	We propose to begin identifying participants for the focus groups in September 2007, and conduct these focus groups in November. Therefore, we hope that it will be easier to locate individuals who participated in Waiver Year Two. In addition, consumers may be more able to remember their experiences under the second year of the Waiver program (although none of the focus group participants indicated that they were unable to remember their experiences from Waiver Year One).

Issue	Description	Potential Solutions/Additional Challenges for Year Two Focus Groups
<p>Selection of focus group participants required significant provider participation, creating potential “independence” issues and requiring cooperation from providers</p>	<p>We selected five providers to assist us in soliciting participation for the focus groups from the consumers they serve based on the providers’ geographic location in the State, as well as, the large number of consumers who received services at these provider locations.</p> <p>Because of the established relationship between the providers and the consumers they serve, they were able to efficiently attract focus group participants. However, it could be suggested that providers are somehow biased in their selection of potential consumers to participate.</p> <p>As discussed in the report, however, there were a relatively small number of participants for providers from which to select. In addition, participants appeared to provide open and free communication about their experiences.</p> <p>Providers were diligent in their willingness to assist in identifying focus group participants and assisting with meeting logistics.</p>	<p>We believe that provider assistance is essential to efficiently obtain participants for future focus groups. Lack of such assistance may impede the number of consumers willing to participate and would require Navigant Consulting to make the initial contact with an increased number of prospective participants to obtain the same level of attendance. The providers that participated in this year’s focus group indicated that initial contact with consumers by Navigant Consulting would not be appropriate and the Division agreed to these arrangements.</p> <p>It appeared to the Navigant Consulting focus group leader that participants were willing and eager to identify both benefits and issues associated with Be Smart, i.e., independence does not appear to have been compromised.</p> <p>We selected four large Health Department providers and one Planned Parenthood provider for the first year focus groups, and propose to select from different geographic areas in the next year. Since the number of Be Smart enrollees is not as concentrated in other geographic areas, we may need to enlist the support of a growing number of providers in the upcoming evaluation years.</p>
<p>Difficulties for consumers in attending focus groups</p>	<p>Some consumers experienced difficulties in attending the focus group meetings, due to factors such as transportation to the meeting site and lack of child care. Those who attended the meetings indicated that they had been able to rely on relatives (in some cases their husbands or partners) to baby-sit while they attended the focus group meetings.</p>	<p>We have identified a number of steps we can take to encourage participation in focus groups:</p> <ul style="list-style-type: none"> • We propose to obtain commitments from a higher number of participants in subsequent years to gain higher participation. • We propose to hold some focus group meetings at a time more convenient for the Be Smart participants – we found, for example, that the mid-day session seemed to generate more attendants in Wake and Guilford counties, for example, because consumers can come

Issue	Description	Potential Solutions/Additional Challenges for Year Two Focus Groups
		<p>during lunch time and the refreshments are adequate for lunch.</p> <ul style="list-style-type: none"> • We propose to identify additional means for reminding the consumers about the focus group, for example, postcard reminders in addition to or in place of telephone reminders. • We propose to consider reimbursing for transportation in addition to/in lieu of part of the attendance stipend.
Lack of male participation in focus groups	As discussed earlier, we did not include males in the focus groups for the first evaluation year because there was an insufficient concentration of males who had received Waiver services in Year One from which to select.	<p>For the Year Two focus groups, we will likely have to contact multiple providers in multiple counties to gather enough participants. An alternative would be to conduct a mail survey to gather information from male participants.</p> <p>We recognize that concerns about potential retribution for problems with child support payments could be an additional barrier to overcome for the male Be Smart enrollees.</p>
Focus group participants may over/under-represent age groups and race/ethnic background	The makeup of focus group participants did not represent exactly the age or race/ethnic background distribution of Be Smart enrollees. Our objective in the Year One review was to secure as many individuals as possible for focus group participation.	We do not recommend random sampling of potential focus group participants because such an approach may not yield the desired number of focus group participants within the areas of the State that focus groups will be held. We will, however, provide a list of participants to providers with a list of priority individuals to achieve as much representativeness as possible.

We also believe that the Year Two focus groups will likely be comprised of individuals with more experience in the Waiver program.

In addition, we expect to see that the results of the activities the Division has taken over the past year to improve outreach about the availability of referral to primary care services. These activities include:

- Distributing outreach materials to local providers

- Training social service staff and provider staff members on the Family Planning Waiver
- Presenting information about the Family Planning Waiver at multiple conferences and exhibitions
- Distributing a recruitment plan to local health care providers
- Developing and distributing a Provider Fact Sheet for local health care providers that gives a general overview of the Family Planning Waiver

Other States' Evaluation Approaches

We contacted staff at other states that also operate family planning 1115 waivers to understand the other approaches to gathering information from Waiver participants. Of the southeastern states which were the focus of our searches, we could find no state that relied on focus groups to gather information from Waiver participants. Two states, Arkansas and South Carolina, used or are planning to use phone surveys, as follows:

- Arkansas, as part of its waiver renewal, plans to conduct a telephone survey with a random sample of waiver clients to assess their experience with receiving and following up with referrals. Outside of the requirements of their waiver evaluations, the Arkansas evaluator partnered with the evaluator in Alabama to conduct a mail survey of family planning providers in both states to determine their referral practices. They followed-up the mail survey with a telephone survey of a sample of clients of providers who responded to the provider mail survey to assess their experience with receiving and following-up with referrals.
- A South Carolina representative stated that the State did not have much success with focus groups in the past, particularly for the population of women of reproductive age enrolled in Medicaid. As part of the waiver renewal application, South Carolina is proposing, beginning in 2008, to evaluate referral to primary care via a telephone survey.

Navigant Consulting recently completed an evaluation of North Carolina's mental health waiver project. As part of that project, we also conducted focus groups. We also recently conducted a series of focus groups in Texas to obtain information about the organization and delivery of case management services across that states' health and human services programs, and our consultants have led numerous other focus groups for various state agencies. From those experiences, we identified a number of "best practices" that we used to conduct the Be Smart focus groups.

These included:

- Obtaining assistance from providers and others who regularly came into contact with focus group participants in enrolling participants
- Providing financial incentives for participation
- Conducting focus groups at sites, that are for the most part, familiar to focus group participants
- Assuring confidentiality of focus group participants
- Achieving desired participation rates in focus groups, which encourages lively and thoughtful discussion

In addition, with the improvements we note above in Table 7, we believe that the focus groups will continue to provide valuable information to support the Waiver evaluation and program improvements as the Waiver continues. We recommend that focus groups continue to serve as the tool for collecting Be Smart participants' comments regarding referrals for primary care services.

Appendix A: Focus Group Questions

Research and Sample Questions for Consumer Focus Groups for the “Be Smart” Family Planning Program

In the table beginning on page 3 we provide the types of questions we identify below.

- **Primary Research Questions (1-8).** These questions contribute to the framework of our evaluation of the programmatic impact of as well as the quality of care provided in the first year of the North Carolina Family Planning Waiver. We will be trying to answer these questions using the consumer focus groups.
- **Questions for Waiver Participant Focus Groups.** These questions will help us to elicit responses from participants to each of the Primary Questions. The intent is for the focus group facilitator to use these questions to help to further frame the conversation around the discussion topic.
- **Additional Questions for Discussion.** We have also provided additional questions that may facilitate more in-depth focus group discussions. These questions may also help to further frame the conversation around the discussion topic, but may not be asked of the focus group participants.

To help the focus group attendees understand the content of the focus group questions we have outlined above, below we have provided some definitions for words or terms used that the focus group facilitator will review with focus group participants prior to the discussion:

- **“Be Smart” Family Planning Program** - The “Be Smart” Family Planning Program is a Medicaid program run by the North Carolina Department of Health and Human Services. The goal of the Family Planning Waiver Program is to increase the number of persons receiving family planning services, decrease the number of unplanned pregnancies and improve the health and well-being of children and families in North Carolina.
- **Eligibility Process** - This refers to the process of determining whether or not a consumer is eligible to participate in the “Be Smart” Family Planning Program. This requires the consumer to fill out an application for the program and, based on information in the application, the State will determine whether or not the consumer meets the requirements for the program, including financial requirements, age requirements, etc.
- **Initial Exam** - For purposes of this focus group, an initial exam has the same meaning as an annual (or yearly) exam. An initial exam is the first annual exam a consumer received upon entry into the program.

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- **Primary Care Provider (PCP)** – A PCP is responsible for meeting basic health care needs and referring patients to other doctors for more specialized issues and conditions. When a condition is present that is not generally treated by the family planning provider, the family planning provider will provide the patient with a referral to the primary care provider. (This will occur only if the provider does not offer free or affordable care.)
- **Primary Care Referral** - When a family planning provider determines that a consumer may have a medical condition/issue that is not covered by the family planning program, the family planning provider should refer the consumer to a primary care provider for treatment of the condition/issue. (This will occur only if the provider does not offer free or affordable care.)

Appendix A: Focus Group Questions

No.	Primary Research Question	Questions for Waiver Participant Focus Groups	Additional Questions for Discussion
1.	Are there increased percentages of enrollees indicating that they heard about Waiver services from one or more sources? (RFP Attachment O, D.1)	<ol style="list-style-type: none"> 1. How did you find out about the “Be Smart” Family Planning Program? Did you hear about the program from more than one source? 2. Did the information you heard/read encourage you to seek services? Please explain. If not, what made you decide to seek services? 3. Was the eligibility process for the “Be Smart” Family Planning Program easy or difficult? Please explain. 4. How long have you been enrolled in the “Be Smart” Family Planning Program? 	<ul style="list-style-type: none"> • Were you aware that you had/have health care issues unrelated to family planning? • Did you seek services just for family planning, or for other health care concerns as well? • Are you aware of what services are covered under the Family Planning Program? • Were you aware of the kinds of services available through the Family Planning Program before enrolling? Or did you find out after you had enrolled?
2.	Are participant women less likely to be lost to follow up? (RFP, Attachment O, C.1.4)	<ol style="list-style-type: none"> 1. Did you receive an initial (yearly) examination when you first enrolled in the “Be Smart” Family Planning Program? 2. After receiving an initial (yearly) exam, have you returned to meet with your provider for services provided under the Family Planning Program? <ul style="list-style-type: none"> ➤ If yes, are these annual (yearly) or periodic (follow-up) visits? Or both? ➤ If periodic (follow-up) visits, how many times per year do you return to see your family planning provider? For what purpose are you visiting the provider? 	

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No.	Primary Research Question	Questions for Waiver Participant Focus Groups	Additional Questions for Discussion
3.	<p>Are participant women more likely to report continuous use of a contraceptive method? (RFP Attachment O, C.1.5)</p> <p>Are participant women more likely to report use of a highly effective method of contraception? (RFP Attachment O, C.1.6)</p>	<p>2. Do you use birth control?</p> <ul style="list-style-type: none"> ➤ If yes, do you use birth control as a result of joining the Family Planning Program? ➤ If no, why not? ➤ How often do you refill your birth control supplies? <p>3. What kind of birth control do you use (i.e., IUD, 12-month of pill use, DepoProvera)?</p> <ul style="list-style-type: none"> ➤ Is the birth control method you use one you use all the time? Or are there months that you don't use it or times during the month that you do not use it (i.e., not taking the pill every day)? ➤ Did you use the same type of birth control prior to enrolling in the Family Planning Program? If no, what did you use? ➤ How did you decide on the kind of birth control to use? 	<ul style="list-style-type: none"> • Were you given choices on what kind of birth control to use?
4.	<p>Are there longer inter-pregnancy intervals among Waiver participants? (RFP Attachment O, C.2.1)</p> <p>Are there lower unintended pregnancies among Waiver participants? (RFP Attachment O, C.2.2)</p>	<p>1. Have you had more than one pregnancy in your lifetime?</p> <ul style="list-style-type: none"> ➤ How long after the birth of your first child was it before you became pregnant again? (i.e., 6 months, 1 year) If you have had more than two children was the time between when you had your first child and your second child about 	

Appendix A: Focus Group Questions

No.	Primary Research Question	Questions for Waiver Participant Focus Groups	Additional Questions for Discussion
		<p>the same as the time between the birth of your second child and third child, and so on?</p> <ul style="list-style-type: none"> ➤ Has this amount of time between pregnancies changed since enrolling in the Family Planning Program? For example, are you waiting more time in between pregnancies to have another child? If yes, how much time are you waiting? ➤ Have you had fewer pregnancies/ children since enrolling in the Family Planning Program? <p>2. Were any of your pregnancies unplanned – i.e., you were surprised to find out that you were pregnant?</p> <ul style="list-style-type: none"> ➤ How many unplanned pregnancies have you had? ➤ Have you had an unplanned pregnancy since enrolling in the Family Planning Program? ➤ Have you had more or fewer unplanned pregnancies since joining the Family Planning Program? 	
5.	What are Waiver participants' experiences in obtaining primary care referrals from family planning providers? (RFP Attachment O, D.2)	<p>1. Do you know what a primary care referral is and why you may need one? <i>(Facilitator may need to define what a referral is.)</i></p> <p>2. Has your family planning provider (e.g. doctor, nurse midwife) ever given you a "referral" to see a primary care provider? Or do you already have a primary care provider that you see when you need to?</p>	<ul style="list-style-type: none"> • Did your family planning provider (e.g. doctor, nurse midwife) explain why he/she was not able to treat you? • Have you been satisfied with the services you have received through the Family Planning Program? If not, why?

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No.	Primary Research Question	Questions for Waiver Participant Focus Groups	Additional Questions for Discussion
		<p>3. Have you been told by your family planning provider (e.g. doctor, nurse midwife) that you need to see a primary care provider for treatment of a particular condition that you might have? Or has your family planning provider (e.g. doctor, nurse midwife) been able to offer you free or affordable care to treat your particular condition?</p> <p>4. Did you have to ask your family planning provider (e.g. doctor, nurse midwife) for a referral to see a primary care provider, or did he/she offer to give you a referral without you asking?</p> <p>5. If you received a referral from your family planning provider (e.g. doctor, nurse midwife), do you understand why your family planning provider gave you the referral?</p> <ul style="list-style-type: none"> ➤ Did the family care provider (e.g. doctor, nurse midwife) give you a list of primary care providers for you to select from? ➤ Did this list include the names and phone numbers to call? ➤ Did the list include the names of free or low cost clinics? 	
6.	How successfully do Waiver participants follow up on primary care referrals obtained from family planning providers? (RFP Attachment O, D.2)	<p>1. After receiving a primary care referral from your family planning provider (e.g. doctor, nurse midwife), did you make an appointment to see the primary care provider?</p> <p>2. If you did not make an appointment to see a</p>	

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No.	Primary Research Question	Questions for Waiver Participant Focus Groups	Additional Questions for Discussion
		<p>primary care provider, why not?</p> <ul style="list-style-type: none"> ➤ What happened? ➤ What problems were encountered? ➤ What are the effects of your not going to see the primary care provider? <p>3. If you made an appointment to see the primary care provider, did you keep the appointment and actually visit the primary care provider? If not, why not?</p> <ul style="list-style-type: none"> ➤ What problems were encountered? ➤ What are the effects of your not going to see the primary care provider? <p>4. If the cost of going to see a primary care provider was too much for you (or there were other issues, i.e., lack of transportation or child care) did you explain this to your family planning provider (e.g. doctor, nurse midwife)?</p> <ul style="list-style-type: none"> ➤ If yes, how did your provider respond? ➤ If no, why not? 	

Appendix A: Focus Group Questions

No.	Primary Research Question	Questions for Waiver Participant Focus Groups	Additional Questions for Discussion
7.	What are the barriers faced by Waiver participants in obtaining primary care referrals from family planning providers? (RFP Attachment O, D.2)	<ol style="list-style-type: none"> 1. If you did not receive a primary care referral from your family planning provider, why do you think you did not receive a referral? 2. Is the family planning provider (e.g. doctor, nurse midwife) unaware of other health care issues you may have? 3. Has your family planning provider (e.g. doctor, nurse midwife) ever given you a referral to another health care provider for medical care, but not to a provider that was right for you? For example, you have limited funds and would need to go to a free clinic or low cost provider and this type of referral was not provided to you? Or perhaps you wanted to see a female provider and you were given a referral to a male provider? 	<ul style="list-style-type: none"> • Did the family planning provider (e.g. doctor, nurse midwife) ask you about any other health care issues you might have? • Do you believe that the barriers you might have experienced in obtaining a referral are typical of what is occurring to all consumers or are these barriers only specific to your situation?
8.	What is the level of satisfaction of Waiver participants in obtaining primary care referrals from family planning providers? (RFP Attachment O, D.2)	<ol style="list-style-type: none"> 1. Were you satisfied with your experience getting a referral to see a primary care provider for your treatment? <ul style="list-style-type: none"> ➤ What factor(s) contributes the most to your satisfaction or lack of satisfaction with your experience receiving referrals? ➤ What would you change to make the experience better? 	<ul style="list-style-type: none"> • Did the referral help you get the treatment you needed?